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THE PATIENTS VOICE AT THE MILLENNIUM

A strange experience

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In order to survive life's traumatic experiences, we tend to push them to one side in our quest for survival. My experience of surgery for epilepsy certainly comes into this category.

My epilepsy is long-standing and dates back to mid-adolescence. The seizures have remained largely intractable to medical treatment and it was only with the advent of routine neuroimaging some years later that it became clear that the cause was a pre-frontal lesion of uncertain diagnosis. At the time, it was decided to watch and wait for any signs of growth or change. Within a year, I began to exhibit signs of a right hemiplegia. I would spill drinks, have difficulty with writing and balance and I started to drag my right foot. A second scan revealed little or no change and mainly because of the position of the lesion and the fact that I had adapted to life with seizures, the advice was to leave well alone.

To say that it was not easy to learn to live with the knowledge that I had a lump in my head of uncertain diagnosis would be an understatement. For 3 years I lived in almost constant terror and torment. I would look at my son and daughter, ten and seven years of age at the time and wonder if I would live to see them grow up. My main concern was that they should not know what I was going through and to carry on as normally as possible for their sakes. I had always exercised, believing that the obvious wear and tear that I was subjected to during convulsive seizures meant that I had to try and keep as fit as possible. Exercise also helped me to cope and prevented my muscles from wasting during the time when the hemiplegia was at its worst and it was encouraging to note a slow improvement in my co-ordination. I was learning to cope. I was also increasingly involved in my work which I enjoyed and this claimed much of my time.

In the Spring of 1994 I suffered a deterioration in my seizures which became increasingly frequent with episodes of partial status. The focal seizure activity affected the right-hand side of my face and eye and after 5 days and sleepless nights, drove me to seek a clinical opinion. I was quite shocked when I was told to go home and rest. Imaging was not suggested, even in the knowledge that I had a lesion in my brain which may have been responsible for this sudden change in seizure presentation. My instinct for self-preservation had always been good and I believe that this saved me from a much worse fate at this time. I felt my former confidence in this clinician melt away and decided immediately to seek a second opinion.

Eventually I was admitted to hospital where I had my first MRI scan. The lesion was said to be anterior to the motor strip and superior to the speech area and it was evident that it had bled previously as well, causing the right-sided weakness and more recently causing my current problems. Resection was spoken of but fortunately it was possible to gain reasonable medical control allowing me to continue my various activities.

Just 6 weeks later, disaster struck. I would suddenly lose my speech and then regain it at about 90 second intervals. This was most unnerving especially to people on the telephone when my sudden silence would be greeted by 'hello? hello?', the line would often then go dead, the caller assuming that they had been cut off.

I returned to the hospital where the speech difficulties were thought to be evidence of a further bleed which was confirmed on a second MRI scan. I realized pretty soon that this was it and that the only option would now be to work me up for surgery and provided that it was thought to be viable, I would have to have an operation or risk permanent deficit, in particular a speech loss or hemiplegia.

The investigations took a week to complete and included a taxing 3 hour functional MRI scan during which I was required to speak to myself for long periods of time and press a button each time my speech abated. Once all the results were amassed and reflected on, I was told that I could have the operation. The problem was that as the lesion was situated in a so-called eloquent area, it would probably have to be done under a local anaesthetic. In other words, I would be awake for the major part of the surgery, receiving general anaesthesia only while accessing the lesion and afterwards while closing up.

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The idea of being awake while the surgeon had his hands in my brain filled me with horror from which there was no escape. I was visited by the surgical team who described in detail what was to happen and I was assured that nothing would take place until I had given my consent. It was small comfort. I was stuck between a rock and a hard place. I could either have an awake craniotomy, a terrifying thought, or face the risk of a permanent deficit. After many visits from friends and family and repeated discussions with my husband, I took the only decision I felt that was open to me. As it was the end of the working week I was sent home for what was to be an emotional 2 days with my family. The last night at home was the worst with its attendant fears that it really would be the last. In the morning, bag packed, I left the house in tears, feeling all my courage had evaporated. My husband stayed calm and positive and more for his sake than for mine, I tried to rise to the occasion.

Once back in hospital, I was visited by the surgical team; a last talk and we were in business. After a fairly sleepless night, despite vain attempts to sedate myself with far too much brandy, there came a knock at the door. I felt like a prisoner on death row being summoned to their execution. My heart sank, I realized that the theatre porters had come to collect me. The ward staff waved goodbye as I was wheeled down the corridor to the lift. A passing registrar remarked inappropriately, 'Cheer up, smile!', my face must have told all. The lift doors clanked shut and had I had the courage to get off the trolley and make my escape I would have surely done so! It was only the constant assurance of my husband which kept me going. I steeled myself not to break down when he left me but failed miserably. I was wheeled into the theatre where preparations began.

One of the first tasks was the attachment of the stereotactic frame which would allow the surgeon absolute accurate calculation of where to access the lesion. All very reassuring but the actual attachment of this frame was far from pleasant. Local anaesthetic was introduced at four points on my head and the heavy frame was then drilled into my skull. I have to admit that it was torture.

With the frame in place I was wheeled down to the CT scanner to check the position for the last time and calculate the setting of the Sexton, rather like that of a ship.

On arrival back in the operating theatre, a general anaesthetic was administered. I had mixed feelings about the expected oblivion and was told that on withdrawal of this anaesthetic, I would wake up instantly. I did. I was conscious of the nurse holding my hand and smiling, while the surgeon talked to me.

The feeling that your brain is open and that the surgeons hands are in it is a very eerie one indeed, in fact when I think back on it now the experience had a surreal element to it. To allow absolute accuracy, cortical electrical stimulation was administered. Seemingly endlessly, I was asked to count backwards from 100, recite the months of the year, days of the week and so on. If my speech was interrupted this meant that the area being stimulated did not represent the optimum way in for the surgeon. Electrical stimulation continued causing my face to contort horribly, my eyes to blink and my hand to jump. Finally the surgeon seemed to be satisfied and told me he was about to resect the lesion. Throughout this period of time there was music playing, some of which had been selected by me and the whole experience had a strange quality about it. The surgeon assured me that everything was looking good and I felt a distinct sense of relief knowing that I was finally being parted from my time bomb.

We had been warned that my speech may be affected or absent completely for some weeks after the surgery and my first real memory is of arriving in the ITU and hearing my husbands voice calling me. I answered him and the realization that I could speak was such a relief that I wept. I checked that I could move my toes and fingers and was overjoyed at the results. I trusted that I was not dreaming my good fortune.

In the following weeks I recovered my strength sufficiently to eventually return to work. Although I am not free of seizures, I now enjoy a better quality of life than I have had in all the years since my epilepsy was diagnosed. Throughout those years it was not possible to control my condition with medication whereas, in the main, it is now. It is hardly possible to put into words what a fundamental relief it is to me to be rid of my time bomb, which had hung over me like a dark shadow for so many years before. The care and support that I received from the medical and surgical team was outstanding and all the more so because of their humility. I have indeed been fortunate in my misfortune.